

Eugenics

## Free speech, democracy, and eugenics

Søren Holm, John Harris

### Attempts to stifle debate in medical ethics must be strongly resisted

On 30 September and 1 October this year a conference on "Ethics, Science and Moral Philosophy of Assisted Human Reproduction" was held at the Royal Society in London. The conference was organised by the German philosopher Edgar Dahl and the eminent embryologist Robert Edwards, and the speakers included scientists, IVF practitioners, and philosophers from the UK, the USA, Europe, and Australia (you can see the programme at <http://www.humanreproethics.org/welcome.htm>).

Because the programme included discussion of preimplantation genetic diagnosis and reproductive choice the conference was targeted by an anonymous group calling itself "People Against Eugenics" that is hiding its real identity behind an email address.

If this shadowy organisation had had any arguments to present it could have participated in the conference, which was not closed in any way. There was ample room for discussion after the talks, as well as a one hour session where it was possible to question individual speakers at length.

However, this organisation either had no arguments or no willingness to stand up and be personally identified. Instead it tried to stop the conference taking place by threatening the Royal Society

with disruption and possible legal action if it allowed the conference to go forward. Luckily this tactic did not succeed, as Robert Edwards agreed to cover any eventual legal costs. This courage deserves the highest praise and admiration.

This attempt to stifle legitimate academic debate about ethical issues is deeply worrying, and must be resisted by the medical ethics community in the strongest possible terms. Unless there can be an open debate where arguments and positions are put forward to be discussed and criticised, not only will the whole field of inquiry wither and die but democratic values will be put at risk.

Think for a moment how the development of medical ethics would have been influenced if people had not been able to discuss abortion and prenatal diagnosis, the issues in research involving incompetent research subjects, or the problems raised by end of life decision making—all controversial issues that in various ways can be linked to eugenics or Nazi Germany.

Free and open debate is the lifeblood of medical ethics—without it medical ethics becomes a dogmatic system devoid of intellectual life. Even those in the medical ethics community who hold substantive views similar to those of the would be conference wreckers

therefore have compelling reasons to uphold the principle that academic debate should not be stifled by political correctness.

At a deeper level the position taken by People Against Eugenics is philosophically confused, performatively inconsistent, and extremely illiberal and antidemocratic. It is philosophically confused because eugenics is not a simple concept with a straightforward denotation and connotation. It is impossible to be "against eugenics" in any meaningful sense, unless we are in a situation where we can openly discuss what we mean by eugenics and it is just this discussion that the organisation wants to stop. It is performatively inconsistent because it denies others the right to speak that People Against Eugenics claims so vociferously for itself (or maybe him or herself: because of its shadowy nature we cannot know whether there is really more than one person behind the name). And it is profoundly illiberal and antidemocratic because free and open debate about controversial issues is not only the lifeblood of medical ethics, but the lifeblood of liberal democracy. Without free and open debate democracy loses much of its justification and becomes a mere counting exercise of votes.

Through their actions "People Against Eugenics" has shown itself really to be "People Against Freedom and Democratic Debate".

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Charlotte Wyatt

## Letting Charlotte die

M Brazier

### The High Court ruling that a premature baby should be not be resuscitated

Late in the afternoon of Thursday, 7 October 2004, Mr Justice Hedley ruled in a highly publicised dispute between parents and doctors about the future care of a severely disabled infant.<sup>1</sup> With sadness, and some reluctance, the

judge held that Charlotte Wyatt should not be subjected to any further invasive or aggressive treatment to prolong her life, despite her parents' insistence that she be given every chance to survive a little longer. The judgment was limited

in scope. The judge did no more than authorise Charlotte's doctors "in the event of a disagreement between the parents and themselves, not to send the child for artificial ventilation or similar aggressive treatment".

The fate of baby Charlotte attracted massive media coverage. Just a week later another dispute between a mother and her child's doctors hit the headlines.<sup>2</sup> A third dispute about the care of an older child also looks likely to end up in court.<sup>3</sup> However, Charlotte's case is unusual only in that the case was heard in open court and because it attracted such publicity. For at least 23 years,<sup>4</sup> the Family Division of the High Court in England has heard a series of cases when parents and professionals have

profoundly disagreed about how best to treat, or not to treat, a very sick baby. As happened in Charlotte's case, the courts have usually,<sup>3</sup> in the end, endorsed the professionals' judgment about the best interests of the infant. The coincidence of three such high profile cases has prompted speculation that parents will now become more ready to "challenge medical authority over the treatment of their children".<sup>2</sup> The assumption that any of these cases is simplistically about the enduring influence of medical paternalism is as wrong as the claim that judicial involvement in decisions about the care of severely ill infants is novel.

### CHARLOTTE'S CASE

Charlotte Wyatt was born at 26 weeks' gestation weighing about 458 g. She has multiple medical problems. All the professionals caring for her acknowledge that she is severely brain damaged and highly unlikely to live for more than a few more months whatever is done for her. She does not respond to stimulation but she does experience pain and distress. Her parents do not dissent from this gloomy prognosis. Her doctors do not seek to withdraw existing treatment from the baby. The dispute revolves around whether if Charlotte stops breathing again she should be ventilated. Ventilation would cause her further pain and distress. Charlotte's parents, who are devout Christians, pray for a miracle and firmly believe that Charlotte can respond to their love and that their child is not ready to die. The judge concluded that, in the light of the evidence that ventilation would not produce significant benefits to Charlotte and would add to her suffering, it was not in her best interests to require that doctors accede to her parents' wishes and ventilate her should she stop breathing. He reached his decision about Charlotte's interests primarily by concluding that, making all allowances for both the doctrine of sanctity of life and the human instinct to survive, Charlotte's life might well be "intolerable". Mr Justice Hedley emphasised that intolerability *per se* was not the legal test. The test is the best interests of the child to which intolerability is no more than a valuable guide. The facts of this particular tragic case have attracted general support for its outcome. I understand that the parents accepted the decision and have chosen not to appeal. The crucial evidence that the process of attempting to resuscitate Charlotte again would cause her pain for no commensurate benefit to her made it inevitable that the judge would

on this occasion endorse the professional judgment. He could scarcely order doctors to inflict unjustifiable suffering on the child in their care.

Other cases are more difficult. What of the infant who survives fed parentally with no prospect of more than a few further months of a life of which she senses little but experiences no pain? What of the child who, if ventilated, may live another 10 years but live a life afflicted by major disabilities—perhaps blind, deaf, and unlikely ever to leave hospital? These are the cases which touch more closely on the thorny issue of quality of life. The decision in Charlotte Wyatt's case will be of little assistance. The sad truth in Charlotte's case was not whether she should be allowed to die but how and when she would die. English law operates on a presumption that parents are the best judges of their children's interests. Parental love and care offers the best prospect of maximising the quality of life of a disabled child. Supporters of Charlotte Wyatt's parents might well argue that, except in the clearest of cases, the parents' view must prevail. Based on the facts of Charlotte's case pro life groups would agree with them, but what of the reverse situation where doctors want to operate to prolong life and loving parents disagree? The courts have in the past overruled such decisions—for example, requiring that a baby born with Downs' syndrome be operated on to remove a potentially fatal intestinal obstruction.<sup>4</sup> Parental choice is not unfettered. Sanctity of life is accorded different weight by different judges. With respect to Mr Justice Hedley, the prevailing factor knitting together most of the diverse judicial reasoning in these tragic cases is intolerance: is the treatment proposed likely to render the continued life of the child demonstrably awful?

**Medical skill now enables babies born at ever earlier stages of gestation to be kept alive**

Every time a court becomes involved in the fate of a sick child, a private grief is exacerbated by the trauma of court proceedings—however kindly the judge seeks to conduct the proceedings. As Mr Justice Hedley says, there has to be a means by which intractable disputes are resolved. The European Court of Human Rights has ruled that when doctors judge that a child should not continue to be treated and parents disagree, the hospital authorities must seek the intervention of the courts, except in genuine

emergencies.<sup>6</sup> Are there better ways to resolve such disputes and could fewer family tragedies end in the courtroom? Months before Charlotte Wyatt's case went to court, I was invited by the Nuffield Council on Bioethics to chair a Working Party examining the ethics of prolonging life in severely disabled fetuses and the newborn. Medical skill now enables babies born at ever earlier stages of gestation to be kept alive. Sadly many such babies die and a significant number of others survive with serious disabilities. Some children flourish and many parents whose children do survive rejoice in their child's life, regardless of its limitations.

Over the next 18 months, the Working Party will attempt to explore whether constructive guidance can be formulated to assist all those involved in making decisions about whether to treat, how to treat, and when to stop treating babies who are profoundly sick both before and after birth. The members of the Working Party—doctors, nurses, social scientists, philosophers and lawyers—begin their task with a range of different personal values and expertise. Two important members of our group come from organisations who work on a daily basis with families of very premature and disabled children. We intend to consult widely in the spring of 2005. We shall not shy away from controversy. Other European jurisdictions are moving to set rules to restrict the resuscitation of babies born before 25 weeks.

The economic implications of neonatal care cannot be ignored. Maybe there is little that can be done by way of guidance in a society that has such radically different opinions on the nature of life and the moral status of the fetus and infant. Each case is in a sense unique, yet not to try is to accept that more grieving parents and concerned professionals will resort, perforce, to the law courts.

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- 1 Re Wyatt (a child) (medical treatment: parents' consent) [2004] EWHC 2247.
- 2 *The Times*, 14 October 2004.
- 3 *The Sunday Times*, 17 October 2004.
- 4 See Re B (A Minor) [1981] 2 WLR 1421 CA.
- 5 One notable exception to this trend is to be found in the case of Re T (a Minor) (wardship: medical treatment) [1997] 1 All ER 906 CA.
- 6 *Glass v United Kingdom* [2004] 1 FLR 1019.